PHIN and Child Health

KIDSNET
Rhode Island Department of Health

Amy Zimmerman,MPH
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About The Ocean State:

- Population of 1 million

- Birth cohort of 13,000

- No Local or County Health Departments

- Health services provided by private physicians, community health centers, hospital clinics

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KIDSNET Mission:

Assure all RI children receive comprehensive screening and follow-up for preventive services

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Historical Context:

- National agenda
- Categorical funding/programs
- Family concerns
- Service delivery concerns

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The KIDSNET Concept

- Public health computerized information management and follow-up system that tracks children's preventive health services

- Links primary care providers to Department of Health

- Promotes sharing of information between providers and programs

- Promotes comprehensive contacts with families

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KIDSNET Affiliated Programs

6 Universal:

- Newborn Developmental Risk
- Newborn Bloodspot Screening
- Newborn Hearing Assessment
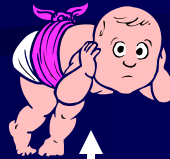- Immunization
- Childhood Lead Poisoning
- Vital Records

4 Targeted:

- WIC
- Early Intervention
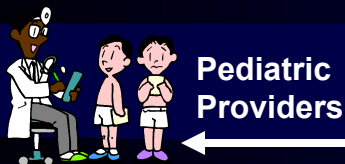- Family Outreach (Home Visiting)
- Birth Defects

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VR2000;
Vital Records and Newborn
Developmental Risks

Home Visiting

Newborn Blood Spot

Pediatric Providers

Lead Prevention

WIC:
Special Supplemental Nutrition Program for Women, Infants and Children

Early Intervention

RIHAP:
Rhode Island Hearing Assessment Program

Immunizations

Rhode Island Department of Health

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Birth Defects

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System Features and Design

- Records initiated at birth

- Includes all RI births from Jan 1, 1997

- Online access by users-via modem

- Data Capture: Only immunization data comes directly from providers

- Data Warehouse Hybrid

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System Design features cont. Follow-up/Outreach:

- Generates well child reminders
- Generates recall letters (lead)
- Provider monthly feedback reports
  - Lead screening
  - Immunizations
- Home Visiting/Risk Response Program

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Progress to date

- 56% of Primary Care Provider sites are participating

- 75% of children in KIDSNET have some immunization history (beyond Hep B at birth)

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Who uses KIDSNET?

Current Users:
      Health department staff
      Health care providers
      Contracted home visiting agencies
      Headstarts

Potential New Users (requesting access):
      School Nurse Teachers
      MCO's
      Audiologists
      School Hearing Screening Program
      Other CBO's

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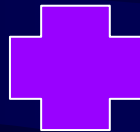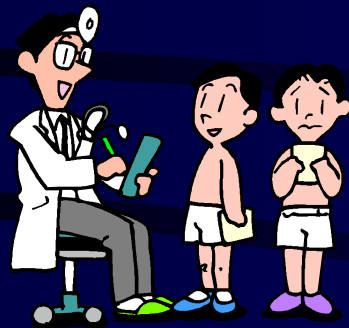# Building of KIDSNET

- 1992-93   Internal planning
- 1994   Obtained a Design Vendor (Maximus):

                 Internal Health Department Assessment

                 Provider Needs Assessment

                 Requirements Specification Document

                 Detailed Design Specifications

                 Wrote RFP for implementation vendor

- 1996   Obtained Implementation Vendor (NSI)
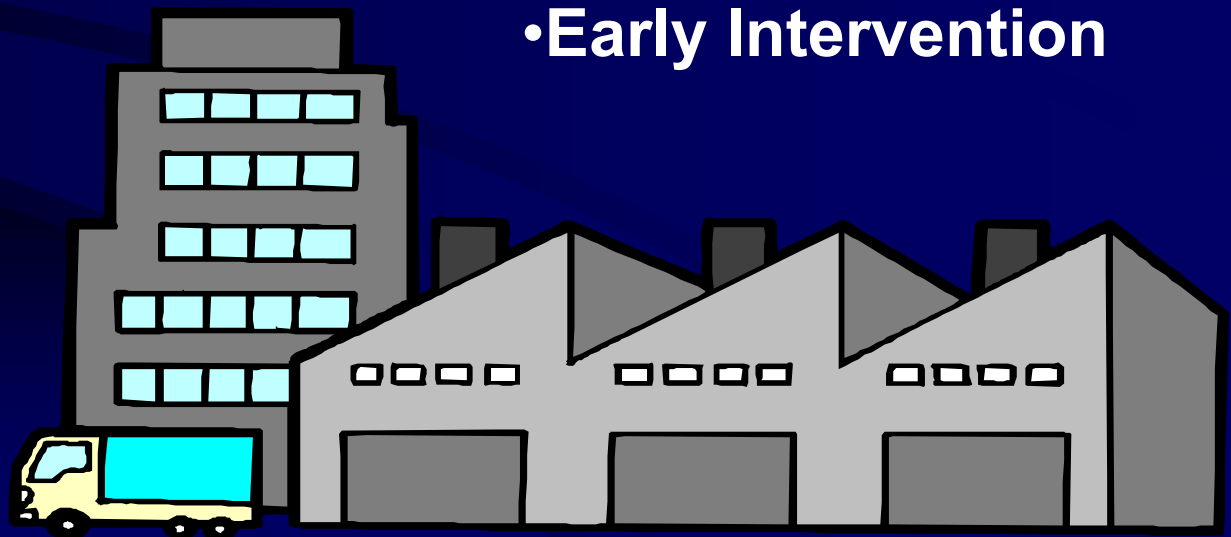- 1997   Pilot testing and statewide rollout

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ORIGINAL DESIGN

Data Warehouse

Immunization Registry

- Newborn developmental risk assessment
- Newborn Hearing
- Newborn blood spot
- Vital Records
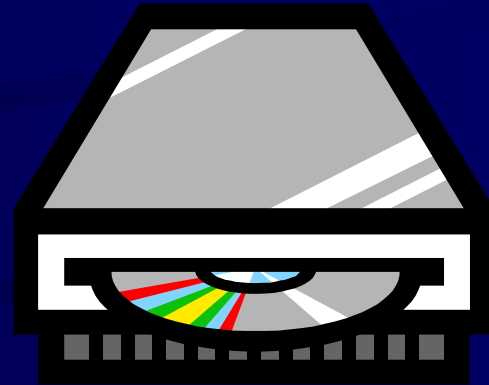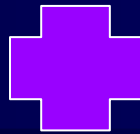- Lead
- Home Visiting
- WIC
- Early Intervention

Building of KIDSNET cont.

1999 Fully Integrated Universal Newborn Screening For Developmental Risk and Home visiting

2000 Integration of Vital Records and data capture for Universal Newborn Screening for Developmental Risk

    Birth defects registry developed and linked

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CURRENT MODEL

Integrated in KIDSNET

Warehoused Data
- Newborn hearing screening
- Newborn blood spot
- Vital
- Lead
- WIC
- Early Intervention
- Birth defects

- Immunization Registry
- Newborn developmental risk assessment
- Home visiting

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Building of KIDSNET cont.

Current and Future efforts:

2003   Technology Improvements- (HLN)

            Integration of VR2000 data capture with
            Newborn Hearing and Heelstick programs

200?   What's Next? Who Knows?

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Future Plans for Technology Improvements:

- Develop front end Web application for accessing data
- Improve (or purchase) matching and de-duplication software
- Develop and pilot PDA data collection tool
- Implement ad hoc query reporting capabilities

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Lessons Learned
Cooperation

- Need executive level support

- Involve constituents early

- Organizational structure impacts internal advocacy/support and span of control

- Negotiate

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Lessons Learned

Cooperation cont.

- Articulate time and staff commitment accurately

- Anticipate some skepticism

- Varying commitment by others

- Reallocation of resources threatens collaboration

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Lessons Learned: Implementation

- Takes longer than expected

- Implementing incrementally has advantages

- Minimize the file transfers, streamline data entry

- Evaluate integration opportunities individually

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Lessons Learned: Technology

- Use highest level of standard technology

- Expect many challenges with linking the data

- Integration drives standard setting

- Integration creates opportunity for reorganization

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Lessons Learned: Staffing

- Train and involve staff early in process

- Staffing up too early can be problematic

- Need for cross training

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Lessons Learned:
Data Usage

- Implement processes to assure data quality

- System not used or accepted until proven beneficial (enough data to make it so)

- Agree on how the data will be used

- Endless opportunities for multi program data analysis

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The Power Of Integration

- Are Lead poisoned children referred to EI and WIC?

- Are Children with a hearing loss referred to EI?

- Does home visiting impact EI, WIC, Lead screening, or Immunization rates?

- Do children with birth defects get preventive services?

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Lessons Learned: Financing

- Multiple sources of funding helpful

- Both startup and maintenance funding will be needed

- Integration efforts not always replace individual costs

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Lessons Learned:
Health Care Environment

- Health Care industry very dynamic

- High staff turnover in health care settings (provider offices)

- Much of health care IT systems for provider offices based on billing-unstable

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Lessons Learned: Summary

- Integration is hard work

- Takes patience and persistence and time

- Takes political will

- Challenges are more programmatic than technical

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Ongoing Challenges

- Keeping up with technology (KIDSNET is being web enabled)
- Matching and de-duplication – working on
- Data capture : "double data entry" – piloting palm application for the field
- HIPPA/Privacy/Security
- Data quality
- Utilizing the data- Feedback
- Maintenance (funding and staffing)-new development
- Success breeds success
- Conformance with PHIN- standards etc.

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In Summary KIDSNET:

- Supports Public Health Infrastructure and promotes economies of scale

- Promotes coordination between programs

- Provides comprehensives interventions and approaches

- Improves access to information and data

- Increases opportunities for data analysis

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RI Informatics Initiative:

- Internal Informatics workgroup created

- SWOT analysis being conducted

- Survey of other states Informatics Initiatives

- Develop a Informatics Strategic Plan

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Contact Information

Amy Zimmerman MPH
Chief Office of Children's Preventive Services
Rhode Island Department of Health
3 Capitol Hill
Providence RI, 02908
(401)-222-5942
amyz@doh.state.ri.us

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